

BARRIERS TO THE APPROPRIATE USE OF COMMUNITY
BASED SERVICES BY FAMILIES OF PERSONS WITH
DEMENTIA

Contract report draft

by

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METHODS OF LOCATING AND ARRANGING HEALTH AND LONG TERM CARE
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PURPOSE

The purpose of this chapter is to describe the factors that affect utilization of community based services among families of persons with dementia, and to develop options to assure more timely and effective use of these services. This chapter will provide background information for chapter 3 of the 1989 OTA assessment Methods of Locating and Arranging Health and Long Term Care Services for Persons with Dementia. Chapter 3 will address family characteristics and their relationship to factors influencing linkage to health and long term care services. The overall purpose of the OTA assessment is to develop and evaluate Federal policy options for improving the existing service delivery system.

FOCUS

In many communities appropriate services for persons with dementia are not available, but even when such services are available, recent research evidence suggests that some families do not use them in a timely or effective way. This chapter will focus on a situation in which certain appropriate services were available, and shall identify factors that may have interfered with their timely and effective use by some families.

This report is based on analysis of existing data from a three-year AARP Andrus Foundation research demonstration directed by Linda K. George Ph.D. and Lisa P. Gwyther MSW at the Duke University Aging Center (George, in press 1988). While the author recognizes that the diagnosis of a dementia or the cause of that dementia is often uncertain, for the purposes of this report, dementia in care receivers is determined by their families, other agencies or health care and social service providers.

DESCRIPTION OF DATA SOURCES

In 1983-84 The Duke Aging Center conducted both a cross-sectional and a longitudinal follow-up study of 500 family caregivers of dementia patients in North Carolina (Gwyther and Brooks, 1983; George 1984a; George 1984b; George and Gwyther, 1986; George 1987; Gwyther, 1987; George and Gwyther 1988). The data from these studies are referenced in the OTA assessment, Losing a Million Minds (1987). These studies were unique at the time for several reasons: (1) the cross-sectional survey of 500 family caregivers for dementia patients was the first broad heterogeneous non-clinical sample of community based caregivers, (2) while it was not a random sample, the white rural character of the sample reflected the income and education distribution of family caregivers from a broad geographic area, (3) the sample included primary and secondary family caregivers, including families of patients residing in nursing homes, (4) the sample reflected national long term care caregiver samples (Doty, 1986; Stone et al., 1987) in the preponderance of older married female spouse or daughter caregivers caring for women over 70, (5) the measures of well-being or burden were derived from scales from which age-matched normative community data was available, permitting comparisons between caregivers and non-caregivers in selected dimensions of well being believed to be most sensitive to the demands of dementia care, (6) evaluation of the effectiveness of community based mutual support groups was possible in the context of a large sample, only half of whom participated in these groups, and (7) the dynamic process of caregiving over time and the specific impact of status changes in the patient and caregiver could be examined prospectively in a large community sample.

Some of the findings from these early cross-sectional and longitudinal studies called into question many assumptions about caregiving. The rich qualitative data available from a limited number of open-ended optional survey questions, when backed by strong quantitative trends, led the Andrus Foundation to fund a three year action

research demonstration based on these findings. A brief review of these findings provides needed background for the questions, hypotheses and design of the Duke in-home respite care evaluation.

THE BURDEN OF CAREGIVING: HOW MUCH? WHAT KINDS? FOR WHOM?

Caring for a relative with a progressive dementing illness implies an acceptance of a long term and presumably permanent imbalance in the normal give and take of family relationships. While families express strong feelings of responsibility, love and commitment, even the most capable and heroic experience frustration, high levels of stress, fatigue and insufficient personal time, all of which threaten to become a significant health care issue in itself. Caregiving can be a normative but stressful adaptive challenge (Brody, 1985). However, the demands of caring for a dementia patient do not, *ipso facto*, produce pathology or burden. What is most impressive in all studies of dementia caregivers is their heterogeneity. This variability is impressive in the differences between primary and secondary caregivers, male and female caregivers, spouse and adult child caregivers, and between racial and ethnic groups. Duke studies of dementia caregivers found that while live-in caregivers may be the largest and the most objectively burdened group, a significant number of secondary caregivers (adult children or those with relatives in nursing homes) experienced high levels of both subjective and objective burden. Male, primarily spouse caregivers, reported less subjective burden than did female caregivers, even when controlling for levels of objective support. In fact, many men seemed to view caring as an opportunity to repay nurturing or replace a lost meaningful work role. Older spouse caregivers are more objectively burdened but adult children may experience more subjective burden. These findings suggest that caregiver well-being cannot be understood without a broad view of the caregiver's subjective perceptions, personal characteristics, and social resources. This diversity among caregivers further suggests that there are probably a variety of options for support which

will all meet the needs of at least some dementia caregivers.

Alzheimer's caregivers did experience substantial decrements in selected dimensions of well-being—mental health, time and satisfaction with time spent in social and recreational participation, and subjective well-being. These families were more isolated and less satisfied with their personal time, they had more stress and mental health symptoms, they used more psychotropic medication and alcohol to cope, and they had more negative affect and lower life satisfaction than normative age-matched samples.

THE ROLE OF OBJECTIVE AND SUBJECTIVE SOCIAL SUPPORT

The subjective adequacy of informal support was measured by asking if a caregiver needed more help from family than he/she received. Subjective perceptions of social support were highly predictive of overall caregiver well-being. Subjective support was also independent of objective support and differentially related to well-being. Caregivers who received a great deal of objective informal support were no more likely to be satisfied with their support than those with little or no help.

If mental health and personal time are most at risk from the demands of dementia care, then it seems reasonable that services designed to provide breaks for caregivers to meet social and recreational needs, or services targeted to the mental health needs of caregivers would be most appropriate. However, increasing the objective support available to a caregiver may not translate into increased satisfaction with the adequacy of that support. At a minimum, Duke findings provide prospective documentation of the positive effects of the perceived adequacy of social support on well-being over time.

Caregiving is a dynamic process which is acutely sensitive to changes in the care context, the caregiver's, and the care receiver's situation. Formal services are not likely

to affect these idiosyncratic or contextual changes. Because caregivers differed dramatically in the types and levels of burden they experienced, no single service program could be expected to restore the well-being or enhance the effectiveness of all dementia caregivers. For example, subjective burden symptoms may respond best to a combination of mutual support group, peer counseling or professional individual family counseling, but live-in caregivers may need in-home respite. Thus, caregivers require a mix of service options that can be activated as circumstances change and resources dictate.

Family caregivers of dementia patients tend to experience different levels of social support over the course of the disease process. Secondary caregivers, other relatives and friends tend to mobilize well at the time of diagnosis, at crisis points or at the death of the patient, but long term support is difficult to sustain. Friends become significant sources of informal support only in the absence of immediate family. Often there is conflict between caregivers and their support networks (Gwyther et al., 1988). Sometimes there are differences over the amount of help offered, which tasks are requested, a primary caregiver's unwillingness to relinquish decision making power or inequitable contributions to patient care.

USE OF FORMAL COMMUNITY BASED SERVICES

Fewer than one quarter of these 500 families used any formal services other than physician care. Overall, caregivers reported very low levels of objective informal or formal support. More than half of the sample reported dissatisfaction with the adequacy of support from family members as preferred providers. When formal services were used, the most frequently used services were part time private sitters or visiting nurses. The timing of formal community based service utilization was most revealing. These services were used predominantly during the final year before the patient's

institutionalization or death. Ironically, patient characteristics, like the severity of disability or behavioral symptoms, were not significant predictors of service utilization or caregiver well-being.

Four factors seemed to predispose dementia caregivers to use of any formal services: (1) younger caregivers, (2) adult child caregivers, (3) caregivers with higher incomes, and (4) spouse caregivers with higher levels of objective social support were more likely to use formal services. While the causal relationships are unclear, younger adult child caregivers may have more competing demands, higher incomes, and greater trust in professional services. Older spouse caregivers who seem to need more assistance but use it least may depend on their active informal networks to link them with formal services.

The formal service users in these early studies expressed overall satisfaction with them, but there was no significant relationship between formal service use and subjective perceptions of caregiver well-being. Service planners might be well advised to select other dimensions of caregiver well-being as anticipated outcomes of formal service use. Subjective well-being seems to be more sensitive to personal or family relationships and resources. The Duke investigators were forced to conclude that fewer caregivers utilize services than circumstances or professionals might suggest are appropriate. (Stone et al., 1987). Relatively isolated spousal caregivers who were intensely involved in full time caregiving were especially unlikely to use formal services.

PREDICTORS OF INSTITUTIONALIZATION

The stated goals of many community based services are to prevent or delay institutionalization. Targeting for such programs requires some determination of persons most likely to be at risk of placement. Duke's prospective longitudinal study of dementia caregivers (Colerick and George, 1986) found seven predictors of institutionalization in

this population, many of which are counter to common assumptions about caregiving:

(1) adult child caregivers were more likely to institutionalize than were spouse caregivers, (2) females were more likely to place their male patients, (3) employed caregivers were more likely to place their relatives, (4) caregivers with high levels of stress symptoms were more likely to institutionalize relatives, (5) caregivers dissatisfied with the amount and quality of personal time were more likely to place their relative (6) caregivers dissatisfied with the amount and quality of social supports were more likely to institutionalize their relatives, and (7) caregivers who used community services within the last year were more likely to institutionalize an impaired relative. Contrary to popular opinion, patient illness characteristics and levels of functional status did not predict placement.

The circumstances of the caregiver, the patient, and caregiving context best predicts placement. If role overload and inadequate social support predicts institutionalization, programs which provide appropriate support and/or lessen overload may be effective, but only if caregivers can be convinced to use them earlier. Even institutionalization itself, had no immediate effect in relieving caregiver burden.

EFFECTIVENESS OF MUTUAL SUPPORT STRATEGIES

An intuitively appealing source of informal support is evident in the rapid development of mutual support groups for Alzheimer's caregivers, i.e., ADRDA. The family caregivers in the Duke sample who participated in these groups felt better supported, less lonely and less misunderstood. They also knew more about dementing illnesses and services available to them (George and Gwyther, 1988). However, there was no significant correlation between knowledge of service availability and service utilization. What this suggests is that support groups can at least assure that underutilization of appropriate services is not the result of lack of information about the

availability of help. Further, these respondents indicated unmet needs for caregiver support beyond mutual support groups (Glosser and Wexler, 1985; Greene and Monahan, 1987; Haley et al., 1987; McCann, 1988). Professionally directed counseling was viewed as particularly helpful in cases of family conflict over care.

SUMMARY

These 1983-84 Duke studies indicated a need for new community service programs and modifications of existing community service programs to make them more available to, useful to, and sensitive to the needs of caregivers of Alzheimer's patients. The tasks of dementia caregivers are both diffuse and nontechnical, but the sheer volume of tasks and time demands on caregivers may outstrip informal resources. The Duke sample indicated that they needed and would use services which were modified to meet the unique aspects of dementia care. Both formal services and informal support can mediate the risks to well being posed by caregiving responsibilities and enhance the quality and effectiveness of family care. However, because objective and subjective social support are independently related to caregiver well-being, interventions and programs should target both dimensions differentially. If formal service use was unrelated to knowledge of service availability, then perhaps the types, intensity, or range of services should be experimentally expanded.

IN-HOME RESPITE CARE: A RESEARCH DEMONSTRATION

Respite care (Gwyther, 1986), offering caregivers temporary breaks from the constant supervision and care responsibilities for an impaired relative, was highly valued by and least available to the original Duke sample. But these early respondents indicated that respite care must be more than available. There was a strong preference for in-home help, particularly from providers who are knowledgeable about the impaired

judgement and behavioral symptoms of Alzheimer's patients. The survey respondents indicated that eligibility for traditional home services was a problem—they had too many assets to qualify for subsidized or free services but too little to hire help privately.

What was most impressive from Duke's original caregiver studies was the emotional investment that caregivers have in their responsibilities. This emotional tone may be reflected in rage at unsympathetic agencies or professionals, fear, grief, advocacy, resignation, humor, but most of all love for and commitment to an impaired older person. With such a strong personal investment, these family caregivers were predictably critical consumers of services and programs in their behalf.

Research on Alzheimer's patients and their families consistently documents their mutual desire to stay in familiar home settings with family care. However, Alzheimer's patients need increasing levels of care and constant supervision which can easily overwhelm the most energetic and committed family caregivers. The unpredictable behavior of dementia patients forces family caregivers to be hyperalert and vigilant in anticipating and heading off catastrophic reactions. These caregivers face significant risks, particularly to their mental health and their time available to meet personal needs. In-home respite programs address this vital need for personal time off from the demands of constant care and supervision. Offering in-home respite services seemed like a good way to recognize family contributions to care. In 1985, however, little information was available on demand or marketing strategies for such services—how to train, organize, deliver or reimburse providers of in-home respite. Duke investigators recognized a need to document positive measurable results in terms of consumer satisfaction or impact on caregivers before determinations of cost and reimbursement would be relevant.

In-home respite has the advantage of greater flexibility and individualization of care. The frequency, intensity, and the service itself can be tailored for each family

unit. Home care is also the fastest growing segment of the health care system. In-home respite services for Alzheimer's families are a response to the growing number of older sicker people whose families have been unable to find the full range of needed services. Therefore, it was assumed that this demonstration service would fill gaps in the long term care system by acknowledging the personal as well as the social and economic costs of chronic illness.

In 1985, the AARP Andrus Foundation funded a three year action demonstration based on the 1983-84 Duke caregiver research. This demonstration served families of memory impaired adults (who could not safely be left alone) in a four county area of North Carolina. Families in a rural two county area were served by a traditional life care community nursing home's nursing assistants, all of whom were trained to provide in-home care. These families also were offered the option of overnight respite care in a designated bed in the ICF facility. Families in a two county area which was primarily urban were served by a traditional proprietary home health agency. Traditional long term care agencies were chosen for ease of replicability, credibility, and well developed administrative structures. Equally important, it seemed unlikely that a free-standing in-home respite agency could meet the changing needs of such a diverse population. The services were available at scheduled times but flexible night and weekend hours were offered to meet convenience and individualization priorities in program design.

The only eligibility criteria were a memory impairment sufficiently severe to preclude staying alone, and residence in the county served by that site. No family was denied access by the ability to pay. Previous Duke studies indicated a strong preference for low cost or subsidized services. Families tend to spend on services based on subjective perceptions of financial adequacy. Subsidies were available up to \$40 per week for up to 20 families per site over a two year study period. Rather than a strict sliding scale, each agency determined its unit cost per hour. Each family was told that

cost and asked what portion of the hourly rate they could absorb. Most families agreed to pay an affordable portion of the hourly rate for the number of requested hours. However, the sample as a whole paid only 20% of the cost of the service. In addition, although families used an average of only 8 hours of in-home respite per week, they indicated a mean preference for 15-20 hours per week.

What is unique about all respite services is the focus on the family as the beneficiary of service. Since family care is a preferred front line source of help, there is a common assumption in the literature that the use of appropriate community services can help to (a) prevent or delay the negative consequences of caregiving on caregivers (i.e., to reduce caregiver burden), (b) to promote the effectiveness and quality of caregiving, and (c) perhaps to prolong caregivers' abilities to provide home care for their impaired older relatives—though the last point is highly debatable and was not an anticipated outcome of this study. This study focused on three general types of outcomes: impact on the providing agencies, impact on the respite care workers, and impact on the caregivers who received respite care services. It was assumed that the provision of respite care in itself would have little direct impact on patient variables.

In this case, appropriate use of service would include use by caregivers of moderately impaired, ambulatory patients who were most at risk from their behavior, and their lack of reason or judgement. Inappropriate use of in-home respite service would be used by caregivers who could safely leave their impaired relatives or caregivers who could use center-based services in a more cost effective manner. The timeliness of the service was a criteria for appropriate use. It was expected that caregivers most at risk of decrements in well-being would be those with constant care responsibilities and little access to informal or formal sources of support.

TRAINING FOR RESPITE PROVIDERS

Previous Duke studies indicated that formal service providers should be knowledgeable about the symptoms, behavior, and language problems of Alzheimer's patients. A significant feature of this in-home respite demonstration was the formal training and clinically supervised practice required of all respite providers. The respite care providers were nursing assistants with one year experience in either a nursing home or home health setting. They volunteered for this demonstration, and they were trained by Duke faculty and supervised by nurse coordinators at both agencies. The training of respite care personnel had several unique features: (1) training was open to all staff of the agency, not just the respite workers, (2) training was open to the community as well, and prospective client families were encouraged to participate, (3) training was add-on and specific to the unique aspects of dementia care rather than traditional personal care training, and (4) agency staff were trained to assume responsibility for repeated trainings necessitated by staff turnover or increasing service demand. For a full description of the training and materials, see the Duke manual (Ballard and Gwyther, 1988).

RESPITE CLIENT CHARACTERISTICS

88% of the care receivers had a diagnosis of probable Alzheimer's, and 50% were over 76 years of age. There were equal numbers of male and female patients, three quarters of whom were white. The racial distribution accurately reflects the agency catchment areas. Nearly three quarters of the patients were night wanderers and most patients were significantly impaired. ADL impairment in this population correlated with the eligibility requirement that they could not safely be left alone.

FAMILY CAREGIVER CLIENT CHARACTERISTICS

100 caregivers received in-home respite from one of the two agencies. 65% of the caregivers were spouses and about 30% were adult-child caregivers. 40% of the caregivers were men, almost exclusively husbands. 30% of the caregivers were black, and they were served primarily by the urban home health site. Compared to the respondents in Duke's earlier longitudinal studies, these respite clients were more likely to be a spouse, male and black. Their financial status was lower than the earlier community sample, reflecting the greater representation of blacks and older spouses on fixed incomes. All caregivers reported financial concerns about future needs which suggests that the subsidized nature of the services was critical. It appears that the program targeting was successful in reaching a particularly burdened group of caregivers.

The respite care clients were more objectively and subjectively burdened than the original Duke community sample. Many respite clients reported significant physical health problems; large numbers of stress symptoms were common, and few caregivers had time for social and recreational pursuits. Spouses were considerably worse off, but overall these caregivers exhibited considerable need for relief from constant responsibility. They were also unlikely, as were our longitudinal respondents, to have used any formal services before in-home respite other than physician care.

FAMILY CAREGIVER OUTCOMES

Family caregiver respite clients experienced a significant increase in time available for social and recreational activities during the receipt of respite services. These clients also experienced measurable increases in their satisfaction with their available personal time and a significant increase in positive moods. Thus, respite care did have modest favorable effects on selected dimensions of caregiver well-being.

Of even greater significance over a six month period of service receipt, these clients doubled their use of other appropriate community services. This suggests that a favorable experience with one service modality, in this case in-home respite care, facilitates seeking and obtaining other relevant community services. The role of the nurse supervisor as assessor, monitor, counselor, and case manager probably figured significantly in this finding.

Satisfaction with the in-home respite service was predictably high. More than 95% reported that the service was helpful, that it provided relief, and that they were satisfied. There were anecdotal positive reports of increased understanding of the primary caregiver's situation by both secondary caregivers, friends, and neighbors. Undoubtedly, these reinforced informal and community networks were perceived as helpful. In addition, caregivers trusted the knowledge and capability of the respite workers. Respite workers became trusted colleagues, teachers and confidantes. These trained nursing assistants played a significant, and quite unexpected role, in family education and support. They taught client families management strategies and tips which were highly valued. The families believed these tips had positive effects on the overall quality of family care, and on the family's continued confidence in providing home care.

Clients had few suggestions for improving the service. However, both clients and providers identified needs for more male respite workers, particularly for large, strong or combative male patients. Complaints were equally rare, but when they occurred, they revolved around the dependability or promptness of the service. Family caregivers came to cherish their time off, and tardiness or absence of the worker was very disappointing. In a similar vein, continuity was critical to a successful respite placement. Families insisted upon having the same worker on a continuing basis, and they would rarely accept substitutes. With too much turnover of assigned workers, some families lost adaptive

energy and dropped out. 40% of the trained respite providers actually worked in the program, and their average length of service was nine months.

EVIDENCE FOR BARRIERS TO APPROPRIATE SERVICE USE

Despite overall positive outcomes from a program designed to be highly responsive to the stated desires of caregivers, only a small portion of the families eligible for the service and who could profit from the service actually used it. One of the stated reasons was cost, but the underlying issue seemed to be fear of future costs rather than current available income. These caregivers had no idea how long care would be needed, and many older spouse caregivers knew they faced the spend down rules of Medicaid before institutional care would be reimbursed. Under those circumstances, many felt that they could not spend even \$10 per week on personal relief.

A second and related issue is the timing of service requests. Our longitudinal study indicated a reluctance to use any formal community services until just prior to institutionalization or death of the patient. Often these service use patterns reflected stop gap measures while waiting for placement. 50% of the Duke respite clients were institutionalized or died within 8 months of entry into the program; 25% of the respite patients died or were placed within 30 days! It was obvious that caregivers were waiting so long to initiate requests for help that terminal care or hospice models were more appropriate than companion level respite care. Under these conditions, it is very difficult to demonstrate that community services are helpful for caregivers or patients. Indeed, the intensity of service needs of these terminally ill patients was often beyond the limits of an in-home respite service. Those families who needed full-time help could purchase that help from a single full-time private, but unsupervised, sitter at much less cost.

The average use of the respite service was just 8 months. Significant predictors of

the length of respite use were: (1) more hours per week spent in caregiving, (2) subjective perceptions of lack of adequate family support, (3) lower income, (4) subjective perceptions of inadequate income, (5) spouse caregivers, (6) less personal time for the caregiver, (7) dissatisfaction with recreational time, and (8) male caregivers. As expected, patient characteristics did not predict length of service use. Unexpectedly, the length of time spent caregiving and the caregivers stress symptoms, use of psychotropic drugs or alcohol, age, race or employment did not predict length of service use.

There were substantial individual and group differences in response to this respite care program, and to some extent, these differences were predictable. Patient symptoms and illness characteristics were unrelated to length of service use or reasons for termination, but caregivers are responsible for use of respite care. It is their characteristics and situations that predict length of service use. Gender and relationship are significant predictors of length of service. Males are more likely to terminate service because of the patient's death, and females are more likely to institutionalize. Spouse caregivers use respite longer, and are more likely to provide home care until the patient's death than are adult children. The perceived need for more family support is more strongly related to length of service use than the objective amount of assistance received from family. Caregivers who institutionalized their relatives had higher levels of objective assistance, but perceived a greater need for family support. Employed caregivers were much more likely to institutionalize their relatives, probably reflecting competing demands on their time and energies.

These findings have specific implications for the capacity of sitter/companion or volunteer in-home respite programs to respond to the needs of dementia families. If service requests are delayed to this extent, it is unlikely that companion or volunteer level providers will have sufficient nursing and personal care skills to meet this need.

SUMMARY OF RESPITE FINDINGS

While there is good evidence that community services can have positive impacts on caregivers, no single service provides total relief for caregivers from the burdens generated by watching a loved relative succumb to a devastating dementing illness. But neither documentation of positive effects nor caregiver knowledge of service availability insures that caregivers will use these programs. It appears that the major conclusion of this study is the need to overcome the reluctance of family caregivers of moderately impaired dementia patients to use appropriate services before in-home respite becomes a hospice model in itself.

This demonstration was initiated with the knowledge that there is some resistance to the use of community based programs by caregivers of demented older adults. Specific strategies to ease access were developed early, but substantial efforts in outreach and publicity (Gwyther and Ballard, 1988) had modest effects.

The features that caregivers indicated were important to them were incorporated in the program design. The service sites emphasized in-home care. Unexpectedly, even with the availability of overnight institutional respite, clients rarely requested this service. In contrast, there were several met and unmet requests for overnight in-home care from the regular respite provider. Respite services were offered nights and week ends, although the majority of the requests were for weekday mornings. The staff were trained to respond to the unique demands of dementia patients and their families. Clients were billed based on self-perceived levels of financial resources, and many received totally subsidized services. Finally, the respite workers provided the same diffuse nontechnical services that family caregivers perform, i.e., they did housekeeping, meal preparation, personal care, companionship, activities and medication supervision.

SUCCESSFUL FEATURES OF PROGRAM DESIGN TO OVERCOME BARRIERS

Several features of this program design were partially successful in overcoming family barriers to appropriate use of services. First, successful matching of respite providers with family clients was based upon careful attention to idiosyncratic preferences and family insistence on continuity. Some workers, in spite of similar training and skills, evoked powerful positive and negative responses from both patients and caregivers. Often it was the worker's gender, age, size, beliefs, race, or appearance that prompted these strong intuitive reactions. It was helpful to accept, rather than oppose, these preferences in order to reassure caregivers that they were still in control. A diverse, creative and stable labor pool makes this task much easier (Gwyther and Ballard, 1988).

Second, families responded well to documentation of expertise. It seemed reassuring to families that respite workers were trained to meet the unique demands of Alzheimer's patients. Specialization certificates for the respite workers enhanced not only their pride and commitment to the program, but the confidence of the family clients. The respite workers were encouraged to view their roles as pioneers. Several family clients thought the workers' pioneer energy and enthusiasm was contagious. Because the workers were experimenting with patient care strategies, some family caregivers became more willing to experiment with new approaches as well. Families drew renewed strength, hope and purpose from the fresh perspective of a skilled new helper.

Third, the role of the nurse supervisor/case manager was central. Families prefer case managers who provide more than brokerage or linkage services. The nurse used her monthly monitoring visits to provide both caregiver and patient services. She screened caregivers for blood pressure or health problems, reviewed and suggested revisions in the patient's care plan, and provided individualized teaching and counseling. As the families

developed trust in the nurse, they were more open to appropriate service referrals. At times the nurse became a buffer against the family caregiver's fear of his/her potential for abuse. The nurse provided an important service as a sensitive objective barometer of a family's tolerance for stress. This monitoring is particularly helpful in isolated home care settings.

Many of these family caregivers could not or would not attend support groups, but they indicated that needs for support were well met through interactions with the respite worker and the nurse. Because the agencies viewed the family as client, frail caregivers were accepted as legitimate care receivers. The diffuse, non-technical and generalist capacity of the respite workers was a strength of the program. Respite workers would take caregivers to the doctor or beauty shop, help with the caregiver's bath, or provide companionship for the caregiver as well as the patient.

Word of mouth referrals built the program, but many families wouldn't use respite until it had proven its viability and acceptance in the community. For this reason, publicity and outreach had to be ongoing, and the pivotal role of providers and clients as referral sources could not be underestimated.

Providers who reflect the indigenous nature of the community were better accepted. Preferences for race or religion of a provider was never tacitly acknowledged, but providers who came from similar backgrounds, or who knew the client when he/she was well, were often more tolerant and accepting of extreme patient behavior or family reactions.

Open training for providers and potential consumers offered a preview of both the workers and their skills. It set a tone in which the providers joined the families in sharing responsibility without overwhelming or taking control away from the family caregiver. Families who received similar training were more likely to use consistent

approaches with the patient. The training was practical, problem focused and positive in offering proactive suggestions for patient activities. This helped some family caregivers become more positive about the potential for improved quality of patient care.

The flexibility of the service also helped to break down barriers. Family clients appreciated respite workers who would follow their relatives into hospitals or nursing homes to ease the transitions. Workers, too, appreciated the opportunity to individualize strategies based on their best judgement. This was more autonomy in the respite provider role than these nursing assistants had experienced in other positions and agencies.

The single most successful aspect of this program was its patient focus. While the respite program was advertised as providing relief for caregivers, it became apparent that few family caregivers see themselves first as a caregiver. They were unlikely to respond to marketing strategies aimed at caregivers. They were equally reluctant to spend on themselves when faced with a deteriorating family member. Successful marketing demanded a patient centered approach. Families responded with enthusiasm if the service was presented in terms of what it could do to enhance the care of their relative. A family's increased feelings of effectiveness and confidence seemed to ameliorate perceived burden.

BARRIERS TO TIMELY SERVICE USE: A SUMMARY

Barriers to appropriate and timely service use may be caregiver based, agency based, or policy based. Agency based barriers are better known and include the need to modify services, settings, and training to meet the unique needs of patients with dementing illnesses. Policy based barriers include eligibility criteria, i.e., considering caregivers as legitimate beneficiaries of service, access, and equity issues in the distribution and availability of a range of needed services. The Duke in-home respite

demonstration, however, uncovered significant personal and familial barriers which deserve further study.

While cost is believed to be a policy or reimbursement issue, it is obviously more complex. The Duke respite clients were not making service decisions on the basis of eligibility or current income levels, but out of fear of future nursing home costs. Given the current spend down policies of Medicaid, and the shortage of Medicaid beds in North Carolina, this fear is legitimate.

Beyond the fear of future costs, there are concerns about the legitimacy of caregiver needs. Although it is often difficult to discern whether the "well" caregiver or the patient is more impaired, spouses seemed particularly reluctant to spend on themselves. Often, they waited until a crisis forced a decision to ask for help. Unfortunately scheduled in-home respite services are not well designed as crisis services.

Another barrier to service use is the dependability and continuity of the service. Alzheimer's caregivers live with unpredictable patients, and changes often come faster than they can adapt. Changes in providers are viewed as unnecessary adaptive challenges, and it becomes easier not to plan on time off rather than to plan and be disappointed.

Convenience barriers to use of appropriate dementia services also deserve consideration. Many Duke in-home respite clients had tried adult day care. Often the frail spouse found it too exhausting to get the patient up, dressed and to a center. Distance was a barrier, and lack of transportation or escort was another. Other family caregivers were uncomfortable with the public nature of day centers and were unwilling to risk having their relative behave inappropriately in such a setting. Several families mentioned the stigma attached to behavioral or psychiatric symptoms. They were unwilling to expose their relatives to potential embarrassment or feelings of failure in

day settings. While this fear of public shame may be unwarranted, caregivers behave based on perceptions of risk rather than objective evidence of poor care in group settings.

Another barrier to appropriate service utilization is the lack of dementia specific training in community service settings. Enlightened and knowledgeable providers offer more security to caregivers, and family caregivers are more willing to trust those with evidence of such add-on training..

An additional barrier to appropriate use of services is a caregiver's perceived lack of control over the service. Individualized in-home services can be tailored to family needs and priorities, but many families initially fear that acceptance of any outside help means relinquishment of family control to strangers. Family caregivers are more likely to use services which extend every opportunity to help the family retain control of patient care.

For many long term family caregivers, it is difficult to imagine that any stranger can invest in and perform personal care tasks as well as the primary caregiver. Further, a typical Alzheimer's patient is likely to fear or mistrust new people or situations. Many dementia patients are unaware of their need for supervision or care. They often react with outrage to the introduction of a sitter. If this occurs, the family caregiver may be reluctant to oppose the patient's strong preferences out of fear of personal reprisals when the worker leaves. Families need help understanding their relative's fears, the basis of these fears in the impaired thinking of the patient, and the family's legitimacy in assuming responsibility for care decisions.

Finally, many family caregivers believe that because their relative is "sick", decisions about care should be made by health rather than social service providers. Many physicians, as preferred providers of health services, are unaware of the extent of family

caregiver burden or of the availability of support services. A family caregiver may prefer to wait until the physician suggests a new care strategy. Even well-intentioned, perceptive physicians may miss the symptoms of caregiver overload.

SUCCESSFUL STRATEGIES TO OVERCOME FAMILY BARRIERS

The preceding summary of family barriers to appropriate service utilization leads to several conclusions. The first is the need to individualize strategies and approaches to meet the needs of such a diverse, yet expanding population of family caregivers. While community education strategies, outreach, and public relations are certainly valuable in enhancing access, most successful referrals or service recommendations depend upon individualized approaches.

Second, very committed family caregivers seem to respond best to altruistic or patient-centered recommendations. Family caregivers value proactive services which enhance the quality and effectiveness of personalized long term care, whether at home or in the institution.

Third, caregiver support services are dignified and acceptable to the extent they are integrated with traditional health rather than social support services (McCann, 1988). For better or for worse, social services still have charity stigmas or custodial implications that pose barriers to the majority of middle class caregivers.

Fourth, case managers should acknowledge individual preferences and acceptability of providers and services in developing service plans. It's difficult to convince a compromised or fragile informal caregiver or network to change entrenched attitudes and behavior patterns. Case management, as a service, is more effective if the manager is also a service provider and a skilled counselor, educator, or health professional, in addition to a service broker or linker.

Finally, the assessment and care planning for dementia patients and their families must go beyond functional assessment, diagnosis, and objective need. Key qualitative criteria for service recommendations can be teased out of answers to the following questions: is the service subjectively affordable? available? appropriate? timely? acceptable? accessible? coordinated? sustained? convenient? dependable? dignified? equitable? family-centered? flexible? professionally directed? safe? secure? Services which meet these criteria are more likely to overcome the traditional barriers of Alzheimer's families to accepting formal services (Gwyther and Ballard, 1988).

OVERCOMING BARRIERS TO SERVICE USE: A RESEARCH DEMONSTRATION

In 1988, the Duke Aging Center began a three year research demonstration to develop and evaluate an individualized intervention designed to help Alzheimer's caregivers overcome barriers to appropriate and timely use of community based services. The intervention is based on information and referral by social workers knowledgeable about (a) the unique demands posed by care of a demented relative, and (b) the services available in various communities. Individualized service plans are developed with the families, and then reinforced, facilitated, and monitored by a single social worker over an eighteen month period. Two intervention models (and a control group) will be compared with the degree of physician participation distinguishing between them. The longitudinal nature of the intervention will be especially important in determining the intervention's effectiveness in meeting changing caregiver and patient needs.

Based on earlier Duke findings of strong caregiver preferences for health related and patient focused services, the intervention is based in an outpatient memory disorders clinic. The intervention models, if demonstrated to be beneficial, will be systematically

codified in brief manuals for ease in transfer to other health settings. Relevant caregiver outcomes to determine effectiveness include: compliance with the service plan, satisfaction with the intervention and services received, positive changes in informal social support, stress symptoms, and social and recreational participation. The cost and time required to provide the intervention is being monitored to develop cost projections for future social work services in health settings. Actual documentation of service use is collected by the clients themselves in a unique diary format from which cost effectiveness of service plans can be imputed.

POLICY CONSIDERATIONS

The attractiveness of respite care or community support policies rests on the recognition of family contributions to long term care and quality of life of dementia patients. The policy interest in respite care or specialized dementia services is both social and economic. People prefer to be at home, and institutional costs of care are escalating and impoverishing families, but family care is not necessarily cheaper. With 3 to 5 people at home as severely disabled as each person in a nursing home, Alzheimer's families are adequately delaying and preventing institutionalization. Of greater policy concern is the accountability, quality, equity, and effectiveness of community services relative to the demands for quality and effectiveness of institutional services. There are probably more cogent moral arguments for respite care based on goals of reducing negative effects on family well being, enhancing family care effectiveness, providing all relevant gap filling services, accepting family caregivers as worthy beneficiaries of prevention oriented services, and achieving equity and quality between and among home and institutional services (Gwyther, testimony, 1987).

The issues of equity and access are value laden and not necessarily economic. Respite services do fill gaps in the range of appropriate long term care services. In-

home services are preferred, and if they can measurably improve the quality, accountability, and effectiveness of family or home care, then, they deserve serious public consideration. In-home respite services are viable options to respond to the diversity of the long term care population in terms of function, available support, and resources. Individuals with dementia constitute perhaps the largest definable population group of those needing long term care (Weller, 1987). As such, the potential for long term care model development is a strong and a hopeful achievement for those facing a variety of progressive or chronic illnesses.

Policy interest in this country is moving from acute to long term care, from patient focused to family focused services and from remediation to prevention of secondary disability in caregivers. Policy makers must consider the foreboding demographic trends. Trends toward more single adults, more childless couples, more divorce and remarriages, fewer children per family, and increased labor force participation of women, all mean future older persons may not have the potential range of family care available today. Respite and community care initiatives may permit more effective local responses.

Current policy suffers from lack of funding for most needed personal care and respite services, arbitrary and confusing separation of health and social support services, and lack of data about how best to provide timely, effectively dosed community services at a bearable cost.